



# Women's Issues Recommendations

## Cross-Cutting Theme Paper

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Prepared by:  
**Mary Worstell, MPH, Co-Chair**  
**Jill Lesser, JD, Co-Chair**

Additional information can be found at the Summit website (<https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>) or the National Alzheimer's Project Act website (<https://aspe.hhs.gov/national-alzheimers-project-act>). The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of HHS, the contractor or any other funding organization.

# **National Research Summit on Care, Services and Supports for Persons with Dementia and their Caregivers**

## **Recommendations for the Cross-cutting Theme of Women's Issues**

**Mary Worstell, MPH, Co-Chair, Cross-Cutting Women's Issues**

**Jill Lesser, JD, Co-Chair, Cross-Cutting Women's Issues**

1. Identify current policies and practices that impede a caregiver's ability to manage or sustain their own health.
2. Differentiate the needs of and effective support mechanisms for diverse sub-groups of caregivers (gender, race, ethnicity, marriage and family status, location, age, sexual orientation, etc.)
3. Identify effective models of healthcare provider integration of caregiver in patient care and care transitions.
4. Study whether medical provider and family expectations of caregivers differ for male caregivers and female caregivers. How are these differences expressed? What is the impact on the caregiver -- positive and negative?
5. Study whether there are differences in the kinds of support that male caregivers need versus the kinds of support that female caregivers need from their families, friends, and the larger community. What are the differences?
6. Study whether male caregivers take better care of themselves than female caregivers do. Why? How?
7. Examine how we are supporting the needs of women, who account for over two-thirds of people living with dementia in the U.S.
8. Examine the impact of historic gender role differences within the elderly population on the lives of people with dementia.
9. Identify the gaps in knowledge regarding sex- and gender-based differences in the progression and expression of dementia that may impact assessing support needs for people with the condition.
10. Study how known sex- and gender-based differences in co-morbidities are managed in people with dementia.
11. Study sex- and gender-based differences that influence caregivers' health and health outcomes. Do the health outcomes and needs of women and men caregivers differ in response to the demands of caregiving?
12. Examine generational and cultural expectations for caregiving responsibilities within families.

13. Identify the gaps in research on the financial impacts of caregiving, particularly given the exacerbating impacts on other economic inequalities for women.
14. Examine medical decision-making in families, which is largely a role occupied by women.
15. Examine barriers to caregiver assessment and application of the results to patient care plans to protect the patient and the caregiver.
16. Identify incentives for the research community to engage a diverse range of people with dementia, including women, and how such incentives are communicated.
17. Study differences in research priorities between people with dementia and caregivers, and include outcomes that are meaningful to both.
18. Determine how people with dementia are being engaged in care research on sex- and gender-based differences.
19. Identify gaps in knowledge about sex- and gender-based differences in care for people with dementia.
20. Identify approaches to improve the care pathways that support informal/family caregivers, 60-70% of whom are women.
21. Identify ways to ensure that advances in effective care and services are made available to underserved communities.
22. Identify ways that formal and informal health service providers can promote and validate self-identification as a caregiver in individuals undertaking these roles. This may increase their awareness of supportive resources for them personally, and for their caregiver responsibilities.